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Healthcare Experiences Among Young Adults Who Identify as Genderqueer or Nonbinary

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Abstract

Purpose: Research on healthcare among gender-diverse populations has largely focused on people who describe their gender in binary terms, either as trans men or trans women. This qualitative study examined the healthcare experiences of young adults who identify as genderqueer or nonbinary (GQ/NB).
Methods: Participants ($N = 10$) were interviewed about experiences seeking and accessing healthcare. All were young adults (ages 23–33) in the San Francisco Bay area who had accessed healthcare at least once in the prior 6 months. A semistructured interview guide elicited conversations about gender identity and experiences of healthcare. Interview transcripts were analyzed using emergent coding analysis to identify themes.
Results: Participants faced unique challenges even at clinics specializing in gender-affirming healthcare. They felt misunderstood by providers who approached them from a binary transgender perspective and consequently often did not receive care sensitive to nonbinary identities. In response to this perceived bias, participants sometimes ''borrowed'' a binary transgender label to receive care, modified the healthcare they were prescribed, or went without healthcare. The GQ/NB young adults in our study regularly felt disrespected and frustrated as they sought and accessed healthcare. Participants felt that the binary transgender narrative pressured them to conform to binary medical narratives throughout healthcare interactions.
Conclusions: GQ/NB young adults have unique healthcare needs but often do not feel understood by their providers. There is a need for existing healthcare systems to serve GQ/NB young adults more effectively.

Keywords: gender-affirming care, genderqueer, LGBT health, nonbinary

Introduction

Increasingly, research is focusing on the health and healthcare experiences of gender-diverse populations.[1] However, this work has focused disproportionately on trans men or trans women, largely ignoring genderqueer and nonbinary (GQ/NB) individuals[2]; that is, individuals who live outside the gender binary and describe their identity as both man and woman, neither, an alternative gender, or as no identifiable gender.[3] Although the newest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has considered such identities in its careful wording of gender dysphoria as a difference between one's experienced/expressed gender and assigned gender,[4] the field is still in need of greater understanding and accommodation of gender diversity in research, clinical practice, training, health, and public policy.[5,6] The limited research with GQ/NB individuals is a reflection of the historically binary narrative of transgender individuals who make a ''transition'' between two clearly delineated gender identities and roles.[7] However, a substantial number of transgender-spectrum people in the United States self-identify as GQ/NB (35% of a recent national sample of 27,715).[8] Hence, there is a need for more research to understand their specific identities, experiences, and healthcare needs.

The transgender and nonbinary communities face significant health disparities, particularly in terms of mental health and HIV-related risks.[1,8–12] These disparities are partly attributable to minority stressors stemming from society's stigmatization of gender nonconformity[13] and the related socioeconomic barriers that affect transgender populations.[14] Findings from the 2011 National Transgender Discrimination Survey further indicate that GQ/NB individuals face even higher rates of harassment, sexual assault, and discrimination in healthcare settings compared to their binary transgender counterparts; GQ/NB youth, in particular, experience higher rates of harassment and sexual assault in K-12 schools compared to binary transgender youth. This survey also found

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Table 1. Participant Characteristics ($N = 10$)

Name	*Age*	*Gender identity*	*Sex assigned at birth*	*Race/ethnicity*	*Sexual orientation*
AJ	24	Genderqueer	Female	White	Queer
Harper	25	Genderqueer, androgynous	Female	Mexican	Queer
Lee	33	Genderqueer, trans	Female	White	Queer
Ren	29	Feminine, other	Female	Asian	Queer
Ryan	24	Genderqueer	Female	White	Queer
Samir	24	Nonbinary, agender	Female	White	Queer
Simone	25	Genderqueer	Female	White	Queer
Skyler	30	Genderqueer, femme, two spirit	Male	American Indian	Asexual
Vera	29	Two spirit	Male	American Indian	Queer
Vern	23	Gender fluid	Female	Asian	Queer

Names given here are pseudonyms.

that 36% of GQ/NB individuals postponed obtaining medical care due to fears of insensitive or incompetent treatment compared to 27% of their binary transgender peers.[9]

The current study explored the healthcare experiences of GQ/NB young adults living in the San Francisco Bay Area. This is one of the first studies to focus specifically on the healthcare experiences of GQ/NB individuals, and while the sample is limited, it provides initial themes to further understand GQ/NB healthcare experiences and opportunities for improvement. Findings from this exploratory study may assist the development of future larger scale studies on GQ/NB individuals' needs in healthcare settings.

Methods

In-depth qualitative interviews allowed us to collect detailed personal accounts of the healthcare experiences of GQ/NB individuals and ultimately present narratives that reflect their unique voices.[15] The study was approved by the Institutional Review Board of San Francisco State University and was conducted during August 2015–March 2016.

Participants

We used purposive recruitment to obtain a diverse sample of GQ/NB young adults, with 50% of the sample identifying within racial or ethnic minority categories. Recruitment included leaving flyers at community spaces and primary care clinics and online postings to social media venues. To be eligible, participants had to self-identify as GQ/NB, be 18 years of age or older, speak English, live in the San Francisco Bay Area, and have accessed healthcare at least once in the prior 6 months. Participants provided written consent before being interviewed. The criterion of having accessed healthcare was defined broadly to include all aspects of gender-affirming care, as well as general primary healthcare, and was not limited to clinics specializing in transgender care. For many transgender-spectrum individuals, affirming transgender care is not simply gender related; it often encompasses all aspects of healthcare,[10] thus we decided to allow participants to expound upon any type of healthcare experience.

Ten interviews were needed to achieve data saturation. Table 1 describes the study sample. The mean age of participants was 27. Eight participants were assigned female at birth; two were assigned male at birth. All participants used the pronoun they/them. Participants were encouraged to self-identify their race and ethnicity; five identified as non-Hispanic White, two as American Indian, two as Asian, and one as Mexican. The majority identified their sexual orientation as queer. Nearly all had health insurance, and the majority ($n = 7$) had health insurance through their employer.

Instruments

We developed a semistructured interview guide focusing on the experiences of GQ/NB young adults as they sought and received healthcare. The interview guide consisted of 12 open-ended questions within three domains: healthcare experiences, barriers, and desired improvements. The guide can be found in Supplementary Appendix SA1 (Supplementary Data are available online at www.liebertpub.com/lgbt).

Procedures

Interviews were conducted by the lead author and took place in private research offices at San Francisco State University and lasted $\sim$1 hour each. Interviews were audio recorded and transcribed. Participants received a $10 Visa gift card as a token of appreciation for their participation.

Analysis

The lead author conducted a content analysis of the transcripts using an emergent-coding approach from the supporting authors. Through analysis, shared experiences and themes were collated across participants and categorized based on themes salient to healthcare access and experience among GQ/NB individuals.[15] This approach allows critical themes to surface across participants and has been particularly useful in health and well-being research.[16] Over the course of emergent-coding, themes were clarified, refined, and established. Representative quotes were selected to illustrate each theme below.

Results

The participants' experiences were categorized into four themes as follows: (1) providers' inability to see beyond the transgender binary; (2) lack of cultural competence in providing GQ/NB care; (3) ''Borrowing'' the trans label; and (4) even transgender-specific services fall short. Each

theme is described further and supported by participant quotes in the next section.

Providers' inability to see beyond the transgender binary

All participants reported that their specific GQ/NB identity and related needs (including but not limited to: diverse gender identity options on intake forms, access to hormone therapy, primary care, and access to inclusive mental health services) were rarely addressed directly by their healthcare providers. While one participant was able to successfully find a support group that was tailored to their needs as a GQ/NB person, this was a peer support group without involvement of health providers, and thus we did not expand upon these interactions. Nearly all participants encountered providers who they perceived to reframe their needs in terms of a binary narrative of transgender care. At times, this was reflected in the offering of prescriptions for hormones or letters of support for gender confirmation surgeries that participants did not request or desire. For example, Samir, a 24-year-old, White, nonbinary, agender participant, spoke to the idea of the transgender binary and how it has affected their experiences of healthcare:

> The standard formula is you get on hormone replacement, and then you get top surgery, and then you get bottom surgery. You would handle all that in those steps. And that's the standard idea in the medical field. And you know that narrative doesn't apply for every binary trans person […] it's even less clear sometimes what people need if you're non-binary.

Similarly, Skyler, a 30-year-old, American Indian, genderqueer, femme, two spirit participant expressed frustration when their provider insisted they consider hormones and surgery:

> I told her about my identity when she asked me. And I remember she asked me if I was a transgender woman. I felt a little taken aback at that but it was understandable, most people like me may be perceived as transgender women. But the problem was after I told her that, it didn't convince her. She asked me if I had ever thought about transitioning, and I told her I couldn't, because I was already male and female. She kept asking me if I had ever considered breasts, or how did I feel about my penis. She was very adamant about it.

Vera, a 29-year-old, American Indian, two spirit participant explained that they ceased medical care because their provider assumed they wanted genital surgery:

> I remember that she [the provider] thought I hated my penis. This was so bizarre to me, you know, because I used it, I was fine with it. But she was seriously like convinced by all this shit that [because] I said I was non-binary that I hated my penis. She told me on—well, she told me like three separate times […] to consider removing it, to consider bottom surgery. Like to transition, whatever that means. She didn't even really believe that I liked using it for sex. I left after the third time, I couldn't take it anymore.

Some participants avoided gender-related care in anticipation of facing a binary transgender bias. Ren, a 29-year-old, Asian, feminine, other participant stated their apprehension as follows:

> My friend, well he's trans and he wanted top surgery and he got it. No question. And he got it here at the clinic, and it was easy for him, um, doctors gave him top surgery. I don't want that though, but I want, maybe a chest reduction surgery, um, but I don't want pecs. I don't want a man torso, just slimmer, I think. So doctors I don't think will do that. So I want different stuff that maybe doctors don't consider as trans surgeries, so maybe they won't do that. I don't think they'll serve me. So why go?

These experiences highlight instances in which the binary transgender narrative permeated healthcare for these participants, and how the corresponding assumptions have serious consequences for GQ/NB people. Participants often felt misunderstood, disrespected, and frustrated with the obstacles they faced in their attempt to receive care, which led some participants to forgo care completely.

Lack of cultural competence in providing GQ/NB care

Participants generally felt that, in addition to a bias toward a binary transgender narrative, their providers lacked knowledge in providing GQ/NB care. For example, Harper, a 25-year-old, Mexican, genderqueer, androgynous participant stated:

> Once you know someone's identity, you can give them the right care. At that point in time, you're no longer guessing what's best for them. […] Would like, would a young person walk into a clinic and the doctor give them an exam for like, Alzheimer's? No, probably not, 'cause they know it's inappropriate. Same kinda thing here. They're wasting their and my time, 'cause I'm not trans, and I don't need trans health stuff. I need genderqueer health stuff, I need androgynous healthcare. Is there an androgynous clinic? No, but there's trans clinics.

Often, participants could not locate providers with knowledge of GQ/NB identities and had to seek additional resources on their own. Some relied on peer support groups, which ultimately could not replace needed healthcare. Some participants described peer support groups as their only means of enhancing their well-being. In the words of Skyler:

> Well I guess the biggest barrier is that people do not understand what two spirit is. They don't know what genderqueer femme means. I have to explain myself every time […] I think that stops me from being able to access services because there's no service for me. I have to make the service myself. I have to make do with what is available and spin it to a person in a way that makes sense for them. That's why my support group is more helpful than any medical doctor.

"Borrowing" the trans label

In many situations, participants found that adopting the ''trans'' or ''transgender'' label enabled them to access services with fewer negative interactions. For example, in the words of Harper:

> But you know, you gotta lie when you go into a clinic, you gotta say you're trans and you gotta say you want hormones and surgery. They're not gonna understand genderqueer, but they're gonna understand trans. […] So I said I was trans a lot, when I wasn't. But I wanted my hormones more than anything else.

However, Samir noted that using the term transgender to access needed services invoked a sense of shame when they were unable to speak authentically about their identity:

> So for a long time I was just telling doctors that I was trans, but that was really tiring because I had to make sure I was saying the right things. And all I really wanted was to explain to someone that I was non-binary, that I wanted to be seen that way. So for a long time I had to put myself on the back burner, because doctors probably wouldn't acknowledge my existence.

Participants often modified the treatment prescribed based on their borrowing of the ''trans label'' because they perceived these prescriptions as not true to their GQ/NB identities. As AJ, a 24-year-old, White, genderqueer participant, explained, they took a lower dose of masculinizing hormones than prescribed to achieve the effect they needed; that is, to appear more ambiguous and less binary:

> Do you know how much easier it is to say trans than genderqueer? I don't get second glances if I just say trans. So what I do is get the full dose by saying I'm trans. But I don't take the full shot every week because I want less effects from T. So yeah, to get the T I have to say I'm trans because I don't want to be questioned.

This alteration of prescribed treatment illustrates that GQ/NB people find themselves making important medical decisions on their own, without the guidance of medical professionals. Participants were aware of the power of claiming a binary transgender identity in terms of healthcare access. By borrowing binary transgender language, participants were able to circumvent the system to obtain healthcare they needed from providers who they perceived to lack the experience to understand the needs of GQ/NB patients.

Even transgender-specific services fall short

Although participants generally believed that transgender-specific clinics would be ideal places to seek care, and nearly all sought healthcare in such settings, they ultimately faced the same transgender binary bias and lack of competency within these settings. Vern, a 23-year-old gender-fluid participant, shared their experience with medical intake forms at a transgender-specific clinic:

> So I went to see a provider, hoping to find some good provider for gender stuff. And this place, it was a trans clinic, but they didn't really know what to do with me, because.. . well they don't really have words for non-binary people. So they didn't have that on the sign up form. When it asked gender, I couldn't click anything. I saw trans, but I knew that the intake form wasn't gonna have what I wanted on there, like, a gender box for me. But I was hoping. I ended up just leaving.

Similarly, Simone, a 25-year-old, White, genderqueer participant, felt that even providers trained in transgender care may lack knowledge and training specific to the needs of those who are GQ/NB.

> And you know, just recognizing too that, they [the providers] might have transgender competency training and all that jazz, but at the end of the day I'm not the kind of trans person you probably got during those trainings. I'm not a man, I'm not a woman. I'm not here for you to just sign off on top surgery, because what if I didn't want that? And no, I don't want a crazy high dose of T, so what then?

In Samir's experience, asking for hormones at a transgender clinic while simultaneously identifying as nonbinary and agender prompted providers to recommend mental healthcare:

> The nurse didn't really know what to do about genderqueer issues, so they just directed me to like, the psych behavioral unit. And the person who took my information from the intake just basically gave me a psych intake, which was actually a lot of questions that really didn't apply to me. And it kind of put more of like a, you know, they had a very heavy behavioral concern for me when I told them I was non-binary. Rather than an ''Okay you want hormones and let's get you in touch with the right people for genderqueer stuff,'' it was more like ''Oh this is very serious and there must be something wrong with you.'' Just because they thought I was having problems about gender. I clearly don't look completely male, so they thought I was suffering. They never thought I just wanted a more ambiguous look.

These experiences highlight that, even within transgender-specific healthcare settings, GQ/NB individuals often felt relegated and marginalized as ''other.'' Clinics often missed opportunities to serve GQ/NB patients by not having more inclusive intake forms and relying on binary transgender assumptions rather than open-ended questions to assess their patients' needs. Despite the hope that a transgender-specific clinic instilled, they often fell short when it came to serving many of our GQ/NB participants.

Discussion

GQ/NB individuals are a substantial and growing subgroup of the gender nonconforming community. Their experience of gender differs from the prevailing binary transgender narrative; rather than ''transitioning'' from their sex and gender role assigned at birth to the ''opposite'' sex and gender role, GQ/NB people identify and express their identity along a spectrum of gender diversity. Findings from this exploratory study indicate that GQ/NB young adults are often misunderstood in healthcare settings. Participants felt that providers—even those with training in transgender care—lack the knowledge, training, and experience to provide them with the healthcare they need. In response to the prevailing gender binary that permeates transgender healthcare, GQ/NB young adults in our study often felt misunderstood, disrespected, and frustrated as they sought and received healthcare.

Participants generally sought gender-related care or, in one participant's words, ''genderqueer health stuff,'' including varying levels of hormone therapy and gender-affirming surgeries. However, the type of care they sought, and the level at which they sought it, did not fit neatly within the predominant binary transgender narrative. Even the experiences of participants who had accessed care at clinics specializing in gender-affirming care illustrated that transgender competency does not equal competency in working with GQ/NB patients. At times, participants had to ''borrow'' a binary transgender label to conform to the binary narrative and access the gender-affirming care they needed, often altering their prescribed regimen. Although this strategy succeeded in obtaining desired levels of medical intervention, it also introduced potential health risks related to not taking medications as prescribed and a lack of open discussion with one's healthcare provider. Other participants ended up avoiding care completely.

Participants desired more GQ/NB-inclusive healthcare, even within transgender-specific clinics. They expressed desires for inclusive intake forms with explicit options for GQ/NB identities, further GQ/NB training for providers, and an enhanced understanding of gender-affirming care that did not rely upon the binary transgender narrative.

The barriers to care illustrated by participants' experiences are particularly disconcerting given the high rates of suicide attempts[17] and experiences of discrimination found among this subgroup of the gender nonconforming population.[9] Existing healthcare service systems are missing opportunities to effectively address GQ/NB individuals' needs for gender-affirming care, primary care, and, when indicated, mental healthcare. Although we did not explore other factors that may contribute to the difficulty in advocating for oneself in healthcare settings (including but not limited to socioeconomic status, social anxiety, and expectations of rejection[18,19]), our findings suggest that healthcare providers could benefit from specialized training to more fully recognize and affirm a spectrum of gender identities and expressions and to look beyond the cross-sex, binary transgender identities of trans man and trans woman. The concerns expressed by our participants could be alleviated if providers actively improved their knowledge of GQ/NB identities and related healthcare needs. In addition to direct interactions with healthcare providers, clinics should revise intake forms to include not only the options of trans man and trans woman but also such options as genderqueer, nonbinary, gender nonconforming, and ''another gender not listed here.''[20,21] Providers should be trained to tailor care to the specific identity and needs of each individual patient. These changes may enhance our current understandings of gender-affirming healthcare to include a focus on the needs of a wider diversity of gender identities and expressions, which may be fluid over time. In sum, gender-affirming healthcare should involve deeper understandings—and fewer assumptions—about patients' identities and healthcare needs.

Limitations

This study was limited by the small convenience sample within the San Francisco Bay Area, a historically supportive area for sexual and gender minority populations. Therefore, our findings can certainly not be generalized to larger populations of transgender and gender nonbinary people in other geographical areas, let alone the entire transgender community. Further studies are needed to ascertain the GQ/NB communities' experiences of healthcare and further understand possible solutions to enhance their experiences. One might reasonably assume, for example, that GQ/NB individuals living in less progressive areas of the United States face even greater challenges. Moreover, because this sample is drawn from a geographic area where GQ/NB identity consciousness is relatively high, these participants may have been more able to identify challenges and articulate their frustrations. Indeed, there is a great demand for additional research carried out with gender diverse samples in a range of geographic areas and settings, particularly rural locations, as well as samples that include greater diversity in age, sex at birth, and level of desire and need for gender-related medical and other healthcare interventions. While there is some evidence that GQ/NB-identified individuals are more likely to be younger,[9,22] which is why we focused on young adults, future studies should also focus on the concerns of older GQ/NB individuals.

We did not have eligibility criteria regarding type of healthcare sought, and included all types of healthcare experiences as participants saw fit. We did not explore whether there was a difference in experiences when seeking general primary healthcare or gender-specific care. Nevertheless, this exploratory study represents an initial step in gaining a better understanding of the critical issues faced by GQ/NB people, an understanding that is necessary to improve their healthcare experiences, reduce disparities, and improve health and well-being. Exploratory studies such as this one collectively will generate hypotheses for larger studies with more representative samples of transgender and nonbinary people in the United States and abroad. In addition, this study provides insight into the experiences of GQ/NB individuals, but does little to understand the perspectives of providers. Future research should also evaluate the experiences and quality of healthcare from the perspectives of providers, patient–provider interactions, and the healthcare systems and settings in which these experiences take place. Such studies should be useful in efforts to enhance the experiences of both providers and patients, ultimately improving the overall standard of care and patients' satisfaction and well-being. Finally, we need more research on GQ/NB identities and their development to contribute to the evidence base on which more tailored interventions can be based.[10]

Conclusion

Gender-affirming care should account for the full spectrum of diversity in gender identity and gender expression. Health information systems, including registration and electronic health records, should be inclusive and affirmative of a range of gender identities and expressions, with opportunities for patients to self-define and describe their particular experience of identity.[23] Provider training is needed to establish a higher level of gender literacy and competence to better serve this patient population and individualize treatment. Current resources from such organizations as the World Professional Association for Transgender Health,[24] the National LGBT Health Education Center,[25] the National Center for Gender Spectrum Health,[26] the Program for the Study of LGBT Health,[27] and the Center of Excellence for Transgender Health[28] provide various opportunities to improve such literacy and competence.

In the interim, we encourage providers to avoid assumptions, ask open-ended questions, listen and learn from their GQ/NB patients, encourage them to relate their unique experiences of identity and health, and engage in the ongoing process of maintaining cultural humility and improving competence and patient satisfaction.

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